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ABSTRACT

This guide is intended to help parents of adolescents and adults with mental retardation to teach their sons and daughters about HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome). An official resolution on AIDS adopted by The Arc, an organization for citizens with mental retardation, begins the guide. This resolution supports continued and increased research, support, and education and does not support mandatory blood testing solely on the basis of mental retardation. Next, basic information about HIV/AIDS for parents is summarized. Specific information that parents should teach their offspring is then outlined. General guidelines for such instruction are offered and include teaching yourself what you need to know, learning about local resources, and repeating and reinforcing the messages. Each of the five guidelines are explained in some detail, and additional resources, such as the SAFE (Stopping Aids through Functional Education) curriculum, are suggested. Specific teaching suggestions for use with daughters are given. A variety of organizational resources, sources for speakers, and hotlines are listed. The guide concludes with The Arc's position statement on sexuality, which stresses the normal human rights of persons with mental retardation. (DB)

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HIV & AIDS Prevention Guide for Parents

Marc Lerro

The Arc
a national organization on mental retardation

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Official Resolution of The Arc

Acquired Immune Deficiency Syndrome (AIDS)

Acquired Immunodeficiency Syndrome (AIDS) is a serious health threat to all people of the world, including people with mental retardation. AIDS is fatal, and during its progression causes mental and physical disabilities in the person who has acquired the disease so that even people who did not previously have disabilities will develop them.

Increasing numbers of infants are being born with AIDS, and most infants who are born with AIDS will be mentally retarded and will have additional mental and physical abnormalities. Children who lack access to adequate health care, live in urban poverty, or have poor health, comprise the vast majority of pediatric AIDS cases. Children and adults can also be infected through blood transfusion.

AIDS is a preventable disease, and education and consequent behavior changes can protect an individual from contracting the disease. Although children and adults with mental retardation are no more susceptible to the disease than other people, education and training efforts must take into account the special learning needs of people with mental retardation. The societal discrimination that is so prevalent in the lives of people with disabilities is amplified when the individual has Human Immunodeficiency Virus (HIV) which encompasses all terms including AIDS, AIDS related complex or the AIDS virus.

The Arc supports:

1. Continued and immediately expanded research efforts for a cure for the disease and amelioration of its effects.

2. Continued and immediately expanded home- and non-hospital based services to support the humanity and dignity of all people with the disease, including people with mental retardation who have the disease.

3. Continued and immediately expanded efforts for prevention of the disease in infants and young children including the provision of AIDS education which is accessible to people of all ages and abilities including people with mental retardation.

4. Continuously updated public education should be made available to persons of all ages and abilities, including people with mental retardation, that will allow the choices and behavior changes necessary for the prevention of the disease in individual cases.

5. A functional approach should be used in describing the service needs of a person rather than the use of the diagnosis AIDS. Services should match needs. The array of services may include but not be limited to: counseling, social services, sex education, employment, residential services, physical therapy, equipment, social work, occupational therapy, early childhood intervention, public education, and nursing. These services should be accessible, nondiscriminatory, and be consistent with the least restrictive environment principle.

6. Every agency should be prepared to face the AIDS crisis by having written policies and procedures regarding staff, volunteers, and consumers who may contract HIV. These guidelines, policies and procedures should be prepared in consultation with interested groups such as individuals, families, health personnel, legal experts, staff, administrators and board members. These policies should cover admission procedures, treatment, confidentiality, due process, hygiene practices, inservice training, prevention issues, and financial responsibilities.

7. Mandatory blood testing or screening for HIV should not be conducted solely on the basis of mental retardation or living circumstances. Testing should not occur without informed consent, a clear medical indication to test, or a real and imminent danger to others. Consent procedures must be followed. Confidentiality must be maintained.

8. Coverage under Section 504 should be extended to persons with contagious diseases.

Adopted as amended
The Arc
Executive Committee
February 20, 1988

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HIV & AIDS Prevention Guide for Parents

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The Arc

a national organization mental retardation

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HIV Prevention Project

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A Message from the President of The Arc

Dear Parent,

No one told us it would be easy raising a son or daughter, especially one with a disability. Our children are growing up in a world much different than the one you and I experienced. That's why it's important to make sure that your family member with mental retardation gets the facts about AIDS and HIV.

For people like me, it may be difficult talking with a young person about sex. But it's absolutely necessary. Even today, many people assume that women and men with disabilities are non-sexual beings. In fact, people with disabilities are just like you and me. They have sexual needs and desires, and they have the right to love and be loved.

Many parents are comfortable with these topics, but others are not. That's why The Arc has developed this guide. You can use this guide to talk about AIDS with your family member. If you prefer to have other people in charge of sexuality education, then this guide will help you make sure that correct information is being provided to your son or daughter.

Please use this guide. Make sure that your daughter or son is getting the facts about HIV/AIDS and other sexually transmitted diseases. AIDS has already taken the lives of many people in our communities, and it will take many more. Only education can stop the spread of this epidemic, and you can be a part of the solution.

Thank you.

Sincerely,

James B. Gardner

James B. Gardner
President, The Arc

What Parents Should Know About HIV/AIDS and Mental Retardation

What is AIDS?

AIDS stands for Acquired Immune Deficiency Syndrome. It is a disease caused by the Human Immunodeficiency Virus (HIV), the AIDS virus.

HIV may live in the human body for years before it causes noticeable signs of illness. It makes people unable to fight other diseases, and these other diseases can be fatal. Someone with HIV infection might look normal and feel healthy, but the virus is still present. Once a person is infected with HIV, he or she is infected for life.

The AIDS / HIV epidemic appeared in the 1970s and 1980s. HIV is now present in countries around the world. It has already infected millions of people, and the numbers are still rising.

How do people get the AIDS virus?

There are three ways to get HIV, the AIDS virus. First, someone can become infected by having unprotected sex with a person who already has HIV. The AIDS virus can be spread during oral, vaginal, or anal sex with an infected person.

Second, someone can get HIV by getting infected blood in her or his body. If a person shares drug needles and syringes, tattoo or piercing equipment with an infected individual, he or she can get the AIDS virus. HIV can also enter through a cut or abrasion of someone cleaning up spilt blood. It can be passed when people become "blood brothers" or "blood sisters."

Finally, babies of HIV-infected women may be born with the infection. HIV can be transmitted before or during birth. If the woman breast feeds her baby, she may transmit the AIDS virus during feeding.

What about people with mental retardation and HIV?

The HIV / AIDS epidemic has a strong impact on people with mental retardation in two ways.

First, adults with mental retardation may be the victims of sexual abuse and sexual exploitation. Even in the age of safer sex, some people still refuse to take precautions. Sometimes, their sexual partners are adults with mental retardation. One study identified 45 adults with mental retardation and advanced HIV infection or AIDS in 44 states (Marchetti et. al, 1989), but it is estimated that hundreds of such cases already exist.

Second, babies born with HIV infections are living longer than ever before, but as they grow, 90 percent have neurological impairment or mental retardation (Ultmann et al., 1987). HIV infection is a cause of mental retardation.

What about testing?

When a person is infected with HIV, his or her immune system begins producing HIV antibodies. Blood tests for HIV antibodies are widely available throughout the United States. These blood tests are not "AIDS tests." They are tests for HIV antibodies. The tests are highly reliable, but not perfect. If someone gets an HIV antibody test within a few weeks or months of infection, the test results may indicate no sign of antibodies even though the person is infected. Counseling by a trained professional should always accompany HIV antibody testing.

Testing for HIV antibodies does nothing to prevent the spread of the disease. Only changing behaviors can stop the spread of HIV and AIDS.

In most communities, the local health department or blood bank can provide counseling and testing at a low cost. Physicians or private health providers may charge more for the same services.

Why not isolate people who are infected?

There are serious legal and ethical reasons against isolating people with HIV infection or AIDS, but there are also several practical reasons against quarantine.

Isolating adults or children with HIV infection will not stop the epidemic. Too many people around the world have HIV. It is impossible to regularly test everyone or to build and maintain the quarantine facilities that would be necessary.

In the United States alone, it is estimated that over one million people are already infected with HIV, with more people becoming infected every day. In general, these people are living longer, healthier lives, thanks to advances in drug therapies and healthier lifestyles. It is hoped that one day AIDS will become a chronic disease, such as diabetes, and may be controlled throughout a person's lifetime.

Can people with mental retardation protect themselves from HIV?

Yes. In communities around the country, people with mental retardation are learning how to protect themselves from the AIDS virus and other sexually transmitted diseases. Materials designed by The

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Arc and other organizations are used to teach safer sex and to reinforce appropriate behaviors. People are learning about their sexual rights and their sexual responsibilities. Some people learn faster than others, and some people require patience and encouragement as they learn to make safer choices.

Materials should always be clear. They should be presented sensitively by trained individuals, or by parents comfortable with the issues. Safer sex training should never be forced upon someone who is unwilling to participate. Because of the sexual nature of the information, training is best offered in small groups or in individual sessions.

What are the sexual rights and responsibilities of people with mental retardation?

The Arc's Position Statement on Sexuality adopted by the delegate body states that The Arc believes that people with mental retardation have the right on an individual basis to:

- have privacy
- love and be loved
- develop friendships and emotional relationships
- choose friends
- learn about sex, sexual problems, sexual abuse, safe sex, and other issues regarding sexuality
- exercise their rights and responsibilities in regard to privacy, sexual expression, and the "pursuit of happiness"
- marry and have children.

The position also states that education should be available for people of all ages to assist in and, where appropriate, teach expressions of sexuality and responsible sexual behaviors with respect for the rights of others. People with mental retardation should be educated and receive proper supports to protect themselves from abuse, exploitation, unwanted pregnancy and sexually transmitted diseases while safeguarding dignity and rights. (The Arc, 1990)

Any individual with a communicable disease such as HIV has a responsibility to attempt, to the best of his or her ability, to prevent the spread of the disease. Since HIV presents no signs of illness for months or years after infection, people who have been sexually active with others may be infected. They should consider whether an HIV antibody test is appropriate. Sexually active adults should know about safer sex, and should use safer sex unless they are attempting to have a child and are certain that they and their partners have no serious communicable diseases.

Women who are thinking about having a baby should talk with their doctors and consider HIV antibody testing before they become pregnant. If a pregnant woman learns she is infected with HIV, she should also be informed that her baby may or may not be infected. Not all babies born to HIV-infected women will themselves be infected.

What about saliva?

Research indicates that HIV is not transmitted through the saliva of an infected person. However, if there is blood in the mouth of the infected person who bites someone else, then HIV transmission might be possible. (Rogers et al., 1990)

What is safer sex?

The only fully "safe sex" is no sex. That is why people use the term "safer" sex. Safer sex involves activities which lower the risk of infection with the AIDS virus and other diseases. Safer sex also reduces the risk of unwanted pregnancy.

Safer sex involves limiting the number of one's sexual partners, minimizing the exchange of body fluids, using water-based lubricants and latex (rubber) condoms, and minimizing the use of drugs or alcohol to enhance sex. Safer sex includes massage, masturbation, and licking or kissing healthy, unbroken skin.

Safer sex minimizes the exchange of semen, vaginal secretions and blood, body fluids containing high concentrations of HIV. The risk of infection from other body fluids is extremely low or nonexistent. Reducing exposure to semen, blood and vaginal secretions during sex almost eliminates the risk of sexually transmitted diseases.

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Safer sex protects people from HIV and other sexually transmitted diseases.

Dangerous activities:

- unprotected vaginal intercourse (without a latex condom)
- unprotected anal intercourse (without a latex condom)
- ingesting urine or semen
- injecting drugs or sharing drug needles
- inserting unprotected fingers into partner
- oral-anal contact
- sharing objects inserted into the vagina or anus

Risky activities:

- oral sex without a condom
- masturbation on broken skin/cuts
- oral sex on a woman
- alcohol, marijuana, other drugs

Safer activities:

- protected vaginal intercourse (with a latex condom)
- protected anal intercourse (with a latex condom)
- wet (French) kissing

Much safer activities:

- dry kissing or licking healthy, unbroken skin
- masturbation/ mutual masturbation on healthy, unbroken skin
- oral sex with a condom
- urination or ejaculation on healthy skin
- touching, hugging, massage, fantasy

What Parents Should Teach About HIV and AIDS

1. AIDS is caused by a virus. The virus is HIV (Human Immuno-deficiency Virus). People can not get AIDS unless they first contract the virus.

2. There are three ways people get HIV from an infected person:
- unprotected sex
- blood
- mother to baby

3. It's not easy to get HIV inside you. It's not spread through the air. It's not spread by casual contact. You can not catch it by touching someone with HIV.

4. The only way to tell if someone has HIV is to get an HIV blood test at a clinic.

5. The HIV virus causes no symptoms, no signs of illness. "You can't tell someone is infected by just looking at them."

6. People with AIDS are very sick and will die. They've had HIV for many months or many years.

7. People with the HIV virus can pass it on to other people if they aren't careful.

8. The HIV virus will be with us for many years, so everyone should know how to keep from getting it.

9. Teach your son or daughter about HIV prevention:

Abstinence:
Don't have sex with another person.

Monogamy:
Have sex with only one person, someone who is not infected with HIV, someone who only has sex with you.

Safer Sex:
If you have sex with more than one person, use latex condoms and water-based lubricants every time. Or, learn about low-risk activities such as mutual masturbation and massage.

Avoid blood:
Stay away from other people's blood. Don't share needles/syringes, don't become blood brothers or blood sisters, and learn to clean up blood safely.

Get an HIV test before pregnancy:
Many women with HIV/AIDS have healthy, uninfected babies, but an HIV test before becoming pregnant is a good idea.

10. Say "no" to unwanted or unsafe sex. No one needs a reason for saying "no." Most people enjoy being sexually active at one time or another. Some people, however, don't want to be sexually active with another person. People should say "no" if they don't want sexual contact, or if the contact is dangerous.

Remember,

a blood test won't prevent HIV or AIDS.

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1.
Teach yourself. There's a lot you need to know. This guide covers most of the issues, but you'll probably want more information.

2.
Learn about local resources. You'll need to know where to turn for answers. You'll find that there are plenty of people who are ready to help.

3.
Get materials you'll need to teach your daughter or son. You'll need to make your message clear. You'll need things for the demonstrations.

4.
Begin teaching your son or daughter. It's hard to talk about sex and HIV. But it gets easier, and it could save your son or daughter's life.

5.
Repeat and reinforce the messages. A person with mental retardation may need to hear the same messages again and again. Even for people without mental retardation, learning how to protect themselves takes time and patience.

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1. Teach yourself. There's a lot you need to know. This guide covers most of the issues, but you'll probably want more information.

After reading this guide, you'll probably still have questions. That's natural. Often, people are embarrassed talking about sexuality and personal issues. That's why there's little or no sexuality education in our schools, places of worship, and other institutions. And that's why it's so important for you to learn the basics and share the facts with your daughter or son.

There are many places to get good information. You might start at the library or at a local bookstore. There are many books and educational videocassettes on sexuality and on AIDS and HIV.

You don't have to be an expert to talk with your family member about sex or AIDS and HIV, but you do need to know the basics. If you still have questions after reading this guide, make a list of the things you want to know.

Remember the basics: HIV is passed from infected people to others in three ways:

- unprotected sex
- blood (exposure to another person's blood, including sharing drug needles)
- mother to baby (exposure before or during birth, or through breast feeding)

Abstinence

Abstinence means not having sex with another person. Some people go through their entire lives without having sex with anyone else. Some parents believe that their son or daughter should not become sexually active, that they should abstain from sex. Other parents believe that sex is a part of a natural maturing process, and that a sexual relationship with someone else will add to the quality of life of a daughter or son. Most people, including those with mental retardation, do eventually have sex.

Abstinence from sex is the only choice that is 100 percent "safe" in terms of sexually transmitted diseases.

Although the percentage of adolescents engaging in sex is increasing, some young men and women today put off having sex until later in life.

The pros and cons of abstinence should be carefully considered. Regardless of whether someone chooses abstinence, sexuality education should still take place. The facts in this guide should still be presented.

Local Resources for HIV/AIDS Education and Training

You are probably surrounded by groups and individuals who are ready to help you teach your family member about HIV. Practically every community has knowledgeable, supportive women and men at the local health department, hospital, or AIDS service organization. Local chapters of The Arc, PTA, American Red Cross, and Planned Parenthood can also help. A list of resource addresses and telephone numbers appears on page 14.

You can learn about these and other local resources by calling the National AIDS Hotline which maintains a list of local community resources for the entire nation.

1-800-342-AIDS (English)
1-800-344-SIDA (Spanish)
1-800-AIDS-TTY (TDD)

Local Resources for HIV Antibody Counseling and Testing

Your son or daughter may be at increased risk of HIV infection if he or she has done any of the following since 1978:

- shared needles or syringes to inject drugs or steroids, or for tattoos or piercings
- (for men) had sex with another man
- had sex with someone suspected or known to have HIV
- had a blood transfusion or blood products between 1978 and 1985
- had sex with someone who has engaged in any of these activities.

The National AIDS Hotline or your local health department can suggest sites for HIV antibody testing and counseling.

Counseling should always happen before and after an HIV antibody test. Counseling is done in private, with only the client and the health care worker present. The health care worker asks personal questions about sex and drug use. With few exceptions, health care workers keep this information confidential or anonymous. (*Confidential* means the health care worker knows a person's identity, but agrees to keep the information private. *Anonymous* means the health care worker does not know a client's identity, and cannot trace the client once he or she has left the office.)

Counseling *before* an antibody test includes an HIV risk assessment. Then, the health care worker offers an explanation of what will happen, such as the drawing of blood. The client will be asked to call or return to the office for results.

Later, when a person receives the test results, the health care worker should continue counseling. If the test is positive, the client should be comforted and encouraged to see a doctor.

The client should learn about HIV-related services in the community. In some cases, people become depressed or angry and require immediate psychological care. Post-test counseling should always accompany test results during a person's return visit.

During both the pre-test and post-test counseling, clients learn about safer sex and other ways to reduce their risks of infection or reinfection.

For people with mental retardation, it is better if this counseling is offered by a professional who understands the disability. If the health department, clinic, hospital, or doctor's office has no one on staff who has such experience, then you might need to be present during the counseling. A family member, close friend, or a professional from a mental retardation agency might also be appropriate. In most cases, the person tested should be the one to decide who will be present.

Can a Parent Be Informed?

You may or may not know if your daughter or son tests positive for the AIDS virus, depending on your personal circumstances and the laws in your state.

Remember that health care workers are bound by state and federal laws regarding confidentiality. Do not ask them to break the laws and ethics of their profession by telling you about your son or daughter's test results.

2. Learn about local resources. You'll need to know where to turn for answers. You'll find that there are plenty of people who are ready to help.

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3. Get materials you'll need to teach your daughter or son. You'll need to make your message clear. You'll need things for demonstrations.

Brochures, videotapes, photographs, and posters are just a few of the things you can use when you talk with your daughter or son about HIV prevention.

You might need to teach the names of sexual and reproductive organs, and photographs or pictures can help. Don't be embarrassed if you hear "street language," but teach your son or daughter the inoffensive names of body parts.

Videotapes on HIV/AIDS are available at no cost through libraries, video rental stores, and social service agencies.

Take your son or daughter with you to the store when you're ready to purchase condoms, water-based lubricants, latex gloves or other items. You can do this before or after your first HIV prevention talk. You might need to reinforce this behavior several times before your son or daughter feels comfortable doing it alone.

SAFE:
Stopping AIDS through Functional Education

The SAFE Curriculum is designed to teach HIV/AIDS prevention behaviors to adults and adolescents with mild to moderate mental retardation. People with severe learning problems might also benefit from SAFE training.

You do not have to be a professional in the field of mental retardation to use this curriculum. You can buy SAFE or borrow a copy from someone else and use it in your home.

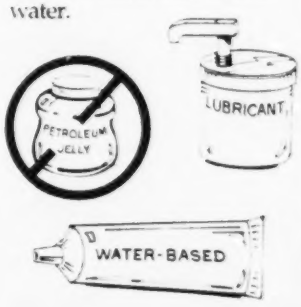
SAFE includes 18 lessons, six VHS video segments, four brochures, 28 35mm slides, and numerous activities. The curriculum costs $60.

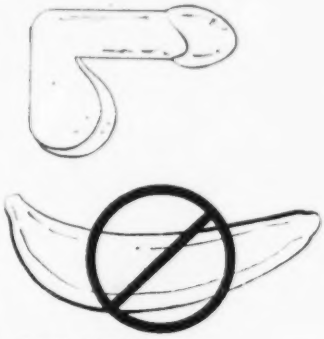
SAFE Curriculum, CDRC Publications, P.O. Box 574, Portland OR 97207-0574 (503) 494-7522

Condoms
Buy only latex (rubber) condoms. "Natural membrane" condoms don't prevent HIV infection. Make sure your son or daughter chooses only latex condoms.

Books, brochures, posters, and other materials are available from health service providers. See "Resources" on page 14.

Lubricants
Oil-based lubricants damage condoms. DO NOT use petroleum jelly, vegetable oils, baby oil, suntan oil or lotion, butter, margarine, or similar products. Only use water-based lubricants when using condoms. Look for the words "water-based" on the box. Some lubricants that won't damage condoms include: K-Y Jelly, H-R Jelly, Lubafax, Ortho-Glynol, Astro-Glide, Koromex Gel, ForPlay, Lubrin, Conceptrol Diaphram Cream/Gel, saliva (without blood), and water.





Penis Model
Use a penis model to demonstrate how to roll on and remove a latex condom. An inexpensive artificial penis can be ordered from an adult magazine or with the help of bookstore operators in your community. You might also borrow one from a family planning clinic or health department. Using a banana or other abstract object as a penis model is not recommended for people with mental retardation.

Plan to spend 30 minutes or an hour during the first session. And expect that you'll need to talk on several occasions during the coming weeks and months.

Make an appointment with your daughter or son. For example, explain that after dinner you want to talk.

Make sure you won't be interrupted by the television, the phone, or other family members.

Don't be surprised by street language or myths that he or she has heard in the community. You might need to offer better names for body parts or for sexual activities, but use words with which you are comfortable.

Always ask if there are any questions. If your daughter or son asks a question you can't answer, say you'll find out later. You might plan to find the answer together. This makes it easier for the two of you to sit down again and talk about sex and HIV prevention.

You can also call a free hotline to get answers about HIV/AIDS, other sexually transmitted diseases, or drug abuse. A list of hotlines appears on page 15.

Take the messages in the "What Parents Should Teach About HIV and AIDS" section on page 10 and start at the beginning. One by one, move through the list of ten items checking off the items you've already covered. Most importantly, be patient. Even with people who don't have mental retardation, it takes a long time and a lot of encouragement to learn how to protect oneself.

Just as you've taught your son or daughter about other topics, teach them about HIV and AIDS. People learn in different ways. You may have to modify the messages for your daughter or son. After you've explained a concept, ask questions of your family member. Questioning him or her will help you understand what points need emphasis and what is already understood.

4. Begin teaching your son or daughter. It's hard to talk about sex and HIV. But it gets easier, and it could save your son or daughter's life.

Even for people without mental retardation, learning how to protect themselves takes time and patience.

Very few people learn things immediately. The same is true for people with mental retardation. After you've talked about HIV and AIDS, look for ways to reinforce and repeat the lessons.

AIDS is in the newspaper and on television almost every day. Media stories can reinforce what you've already taught.

Repeating the lessons helps to reintroduce the important concepts of HIV prevention. Some points will have been forgotten. Other points might have been misunderstood, or might have been altered over time. Repeating the lessons a few months or a year later will remind both of you about the importance of the epidemic and personal choices.

The home is a good place to start reinforcing HIV prevention messages. But it's not the only place. HIV education should be a part of school, church, and agency programs as well. AIDS awareness posters and brochures are available at no cost from local health departments, agencies, and from the National AIDS Clearinghouse.

5. Repeat and reinforce the messages. A person with mental retardation may need to hear the same messages again and again.

Demonstrations and Illustrations

People with mental retardation learn best when all their senses are involved. Using photographs, illustrations, and demonstrations makes learning easier.

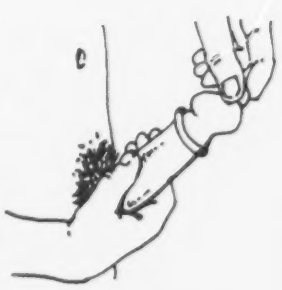
Illustrations

Drawings may help as you talk about specific body parts, or about sexuality in general. You can point to pictures to make sure that you and your daughter or son are talking about the same body parts. You may prefer using pictures of people in sexual positions. A good source for free materials is the library. Libraries carry books and other materials that you can use for your discussion. Librarians will probably suggest materials from their art, science, or social sciences collections.

Demonstrations

If you plan to talk about using condoms and lubricants, it is important to demonstrate how they are used. Talking about condoms and lubricants must be a complete discussion and must involve practice. If you are uncomfortable showing pictures to your daughter or son, or conducting demonstrations, ask a family friend, an older brother or sister, or someone else you trust.

Using Condoms



Pinch the tip of the condom. Put it on the end of your penis.

Unroll the condom, all the way down to the pubic hair.

After sex, hold the base of the condom as you pull out of your partner.

Keep semen inside the condom. Throw the condom away.

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Teaching Your Daughter About Safer Sex

Men are often the focus of HIV prevention training, but women should learn about safer sex, too.

Sexually active women are at risk of HIV infection. Women may become infected through unprotected sexual contact with an infected partner. Some people with HIV do not tell their sexual partners about the infection. And when asked, some say they are "healthy" or "don't have any diseases." Sexually active women need to learn about protecting themselves, and they should follow HIV risk reduction practices each time they have sex.

Because of the physical differences between men and women, it's much more likely that a man will transmit HIV to a woman than a woman transmitting the virus to her male partner.

Using Condoms, Lubricants, and Barriers

Your daughter needs to know that she shares the responsibility to protect herself during sex. She needs to know how to get condoms, water-based lubricants, gloves or any other barriers she might use when having sex.

If your daughter is sexually active, she should have condoms and water-based lubricant in a convenient, appropriate place, such as her purse or her bedroom.

Condom Demonstrations

Teach your daughter the importance of using condoms. She should know that putting a condom on her partner can be an enjoyable experience all by itself. She should also know about carefully removing a condom from her partner, placing it in a tissue, and disposing of it without spilling semen. Just as men need practice with condoms, so do women.

Pregnancy

HIV antibody testing and counseling is a good idea for many couples who are planning a pregnancy. If a woman is already pregnant, and she is HIV infected, she needs to know that some babies born to infected mothers are born without the virus.

Saying "No"

Saying "no" to unwanted or unsafe sex is a life-saving skill. Saying "no," even to a long-term partner, is a personal choice. A woman should understand that she has the right to say "no" for many reasons:

- she does not feel like having sex at a particular time
- she may not feel well, either physically or emotionally
- she does not want to have unprotected sex, even if a partner claims to be "healthy"
- she does not wish to risk an unwanted pregnancy.

You can practice with your daughter, having her say "no" in a variety of situations. For example, you can play the role of a friend who wants to go to a movie that your daughter doesn't want to see.

In SAFE: Stopping AIDS through Functional Education (page 10), several activities present different ways to teach a person with mental retardation to say "no."

Making Sure Other People Teach The Facts

Education concerning AIDS must start at the lowest grade possible as part of any health and hygiene program.

Former Surgeon General
C. Everett Koop
Surgeon General's Report on Acquired Immune Deficiency Syndrome

Make sure other people teach the facts about AIDS and HIV.

1. Read "Basic Concepts to Teach About HIV and AIDS."

2. Contact your local school, place of worship, or social service agency to arrange a meeting. Let them know that you want to talk about their HIV/AIDS education plan.

3. During your visit, ask to see the HIV/AIDS education materials (brochures, posters, teaching plan, videotapes, etc.).

4. Compare the materials to the information in this guide and other HIV/AIDS publications. If there are discrepancies, ask the staff member to explain the differences.

5. Ask how you can help with HIV/AIDS training in the school, place of worship, or social service agency.

6. If the HIV/AIDS information is incomplete or inaccurate, then offer to help improve the program. If your offer is rejected, remain calm and arrange a meeting with representatives of the board or governing body of the agency.

Resources

These organizations offer training and materials on HIV/AIDS, sexuality, disabilities, and related topics.

The Arc
500 E. Border St., #300
Arlington TX 76010
(817) 261-6003
(817) 277-0553 (TDD)

American College Health Association
1300 Piccard Dr. #200
Rockville MD 20850
(301) 963-1100

American Foundation for AIDS Research (AmFAR)
1515 Broadway, #3601
New York NY 10036-8901
(212) 719-0033

American School Health Association
P.O. Box 708
Kent OH 44240
(216) 678-1601

National AIDS Clearinghouse
P.O. Box 6003
Rockville MD 20849-6003
(800) 458-5231

National Education Association Health Information Network
1590 Adamson Pkwy #260
Morrow GA 30260
(404) 960-1325

SF AIDS Foundation
333 Valencia St., 4th Floor
San Francisco CA 9410
(415) 964-4376

Sex Information and Education Council of the U.S. / SEICUS
130 W. 42nd St., #2500
New York NY 10036

For a speaker for schools, places of worship, or social service agencies, contact:

- your state, county, or city health department
- your local hospital
- your local AIDS service organizations
- your local American Red Cross chapter
- your local PTA chapter
- your local Planned Parenthood clinic
- your local chapter of The Arc.

Hotlines

National AIDS Hotline
(800) 342-AIDS English
(800) 344-SIDA Spanish
(800) AIDS-TTY TDD

National Sexually Transmitted Disease Hotline
(800) 227-8922

National Drug Abuse Treatment Hotline
(800) 662-4357 English
(800) 66AYUDA Spanish
(800) 288-0427 TDD

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The Arc

Position Statement on Sexuality

Issue

Sexuality is a natural part of every person's life. Sexuality and sexual expression of people with mental retardation creates diverse reactions. This issue requires respect, understanding, caution and an awareness of the wide array of human rights. Current social trends make the issue more urgent and complicated. The commitment to full integration into the community has given people with mental retardation new experiences, more risks, and more opportunities to make choices. The ability to make educated choices in the area of sexuality is especially critical.

Position

The Arc recognizes and affirms that individuals with mental retardation are people with sexual feelings, needs and identities, and believes that sexuality should always be seen in the total context of human relationships. Sexuality includes gender identity, friendships, self-esteem, body image and awareness, emotional development and social behavior, as well as involvement in physical expressions of love, affection and desires.

The Arc believes that people with mental retardation have the right on an individual basis to:

- have privacy;
- love and be loved;
- develop friendships and emotional relationships;
- choose friends;
- learn about sex, sexual problems, sexual abuse, safe sex, and other issues regarding sexuality;
- exercise their rights and responsibilities in regard to privacy, sexual expression, and the "pursuit of happiness;" and
- marry and have children.

The Arc supports programs which encourage people with mental retardation to develop expressions of their sexuality that reflect their age and social development, acknowledge the values of their families and are socially responsible. The Arc believes education should be available for people of all ages to assist in and, where appropriate, teach expressions of sexuality and responsible sexual behaviors with respect for the rights of others.

In support of this position, The Arc will advocate that the person with mental retardation be educated and receive proper support to protect him/herself from abuse, exploitation, unwanted pregnancy and sexually transmitted diseases while safeguarding dignity and rights.

The Arc further advocates that on an individual basis people with mental retardation have the right to receive sex education, to marry, to have children if they so desire, and to receive proper supports to assist them in rearing their children. Furthermore, The Arc believes that the presence of mental retardation regardless of severity, must not, in itself, justify either involuntary sterilization or denial of sterilization to those who choose it for themselves.

Adopted by The Arc Delegate Body November 10, 1990

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This publication has been reviewed and approved by The Arc's HIV Program Review Panel for use by parents of people with mental retardation.

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